

Care for Children and Adolescents With Cancer: Questions and Answers

Key Points

- Children's cancer centers are hospitals or units in hospitals that specialize in the diagnosis and treatment of cancer in children and adolescents (see Question 1).
- Several groups have established standards for children's cancer centers or programs (see Question 2).
- Children with cancer can receive treatment in clinical trials (research studies) at the National Institutes of Health Clinical Center in Bethesda, Maryland (see Question 9).
- A child's pediatrician or family doctor often can provide a referral to a children's cancer center (see Question 10).
- Organizations are available to offer support to families, including help with transportation, lodging, and financial assistance (see Question 11).

Survival rates for childhood cancer have risen sharply over the past 25 years. In the United States, more than 75 percent of children with cancer are now alive 5 years after diagnosis, compared with about 60 percent in the mid-1970s (1). Much of this dramatic improvement is due to the development of improved therapies at children's cancer centers, where the majority of children with cancer have their treatment.

1. What are children's cancer centers?

Children's cancer centers are hospitals or units in hospitals that specialize in the diagnosis and treatment of cancer in children and adolescents. Most children's, or pediatric, cancer centers treat patients up to the age of 20.



2. Are there standards for children's cancer centers?

The following groups have established standards for children's cancer centers or programs:

- The National Cancer Institute (NCI)-sponsored Children's Oncology Group (COG), formerly two separate groups known as the Children's Cancer Group (CCG) and the Pediatric Oncology Group (POG), is a network of children's cancer centers that meet strict quality assurance standards.
- The American Academy of Pediatrics (AAP) published *Guidelines for the Pediatric Cancer Center and Role of Such Centers in Diagnosis and Treatment* in 1986 and 1997. The document is currently being revised.
- The American Society of Pediatric Hematology/Oncology (ASPH/O) established standard requirements for programs treating children with cancer and blood disorders.

These groups agree that a childhood cancer center should be staffed by a team of trained pediatric oncologists (doctors who specialize in childhood cancer) and other specialists. Other members of the health professional team usually include pediatric surgeons, specialist surgeons (for instance neurosurgeons and urologic surgeons), radiation oncologists, pathologists, nurses, consulting pediatric specialists, psychiatrists, oncology social workers, nutritionists, and home health care professionals—all with expertise in treating children and adolescents with cancer. Together, these professionals offer comprehensive care.

3. Why might a family look for a specialized children's cancer center when a child or adolescent is diagnosed with cancer?

Because childhood cancer is relatively rare, it is important to seek treatment in centers that specialize in the treatment of children with cancer. Specialized cancer programs at comprehensive, multidisciplinary cancer centers follow established protocols (step-by-step guidelines for treatment). These protocols are carried out using a team approach. The team of health professionals is involved in designing the appropriate treatment and support program for the child and the child's family. In addition, these centers participate in specially designed and monitored research studies that help develop more effective treatments and address issues of long-term childhood cancer survival.

4. When children go to a specialized cancer center, does it mean their treatment will be part of a research study?

Not necessarily. Participation in research studies is always voluntary. Parents and patients may choose to receive treatment as part of a clinical trial (research study); only patients and parents who wish to do so take part. However, a large number of children who go to pediatric cancer centers take part in clinical trials. About 70 percent of

children with cancer are treated in an NCI-sponsored clinical trial at some point during their illness.

5. What is a clinical trial or research study?

In cancer research, a clinical trial is a study designed to show how a particular strategy—for instance, a promising anticancer drug, a new diagnostic test, or a possible way to prevent cancer—affects the people who receive it.

Treatment clinical studies fall into three categories:

- Phase I studies evaluate what dose is safe, how a new drug should be given (e.g., by mouth, injected into a vein, or injected into the muscle), and how often. Phase I trials usually include a small number of patients and take place at only one or a few locations.
- Phase II studies investigate the safety and effectiveness of the treatment, and study how it affects the human body. Phase II clinical trials usually focus on a particular type of cancer, and include fewer than 100 patients.
- Phase III studies, which usually involve a larger number of patients at many locations, compare the new treatment (or new use of a standard one) with the current standard therapy (see below).

6. What are the benefits of taking part in a clinical trial?

One advantage is the possibility that a new treatment (or diagnostic test or preventive measure) will turn out to be better than a more established method. Patients who take part in approaches that prove to be better have the first chance to benefit from them. In phase III clinical trials, in which one treatment is compared with another, patients receive either the most advanced and accepted treatment for the kind of cancer they have—known as the “standard” treatment—or a new treatment that has shown promise of being at least as beneficial as the standard treatment.

People who take part in clinical trials receive specialized care under a very precise set of directions, or protocol. To ensure quality care, highly trained and experienced cancer specialists design, review, and approve each protocol. In addition, all participants in clinical trials are carefully monitored during the study and are followed afterwards. Participants are often included in a network of clinical trials carried out around the country. In this network, doctors and researchers share their ideas and experience, and patients receive the benefit of the shared knowledge.

7. What are the risks of taking part in a clinical trial?

Clinical trials can involve risks as well as benefits. All cancer treatments have side effects, but treatments being studied may have side effects that are not yet understood as

well as the side effects of standard treatments. The potential risks and benefits of each study are explained during the informed consent process, when patients and families discuss all aspects of the study with their doctors or nurses before deciding whether to participate.

8. What about costs? Do insurance or managed care plans cover treatment at a children's cancer center?

Some health plans cover part or all of the cost of care at children's cancer centers, but benefits vary from plan to plan. Questions or concerns about health care costs should be discussed with a medical social worker or the hospital or clinic billing office. Financial assistance and resources to cover health care costs may be available.

9. Can children with cancer be treated at the National Cancer Institute?

Children with cancer can receive treatment in clinical trials at the National Institutes of Health (NIH) Clinical Center in Bethesda, Maryland. Two branches of the NCI that study specific types of cancer have their own contact points:

- **The Pediatric Oncology Branch (POB)** conducts clinical trials for a wide variety of childhood cancers (except brain tumors) at the NIH Clinical Center. To refer children, teenagers, or young adults, call the POB office at 1-877-624-4878 between 8:30 a.m. and 5:00 p.m. Eastern time. An attending physician will return the call, determine whether the patient is eligible for a research study, and help arrange the referral. More information about the POB can be found at <http://home.ccr.cancer.gov/oncology/pediatric/> on the Internet.

Attending physicians in the POB are also available to provide a second opinion. The patient, family member, or health care provider can contact the POB to talk about a diagnosis or treatment plan.

- **The Neuro-Oncology Branch** offers a large number of clinical trials as well as consultation for children with brain tumors. Staff can provide a second opinion for doctors, patients, and family members who are interested in this service. Specialists can either evaluate the patient in person or review the patient's medical records and scans.

To find out more about this service, and what information is needed, contact the Neuro-Oncology Branch at 301-402-6298 between 9:00 a.m. and 5:00 p.m. Eastern time. The Branch's Web site can be found at <http://home.ccr.cancer.gov/nob/default.asp> on the Internet.

10. How does a family find a children's cancer center?

A child's pediatrician or family doctor often can provide a referral to a children's cancer center. Families and health professionals also can call the NCI's Cancer Information Service (CIS) at 1-800-4-CANCER to learn about children's cancer centers that belong to the Children's Oncology Group (COG). All of the cancer centers that participate in these Groups have met strict standards of excellence for childhood cancer care. A directory of COG institutions by state is also available at <http://www.curesearch.org/resources/cog.aspx> on the Internet.

11. How do families cope with practical issues like getting to a treatment center and finding a place to stay near the center?

Many families receive helpful information from their doctors and nurses. Treatment centers often have social work departments that can provide assistance. In addition, various organizations offer support to families, including help with transportation, lodging, and financial assistance. Sources of help include the following organizations:

The Candlelighters Childhood Cancer Foundation. Candlelighters is an international organization of parents whose children have or have had cancer. It offers information and assistance to families through a national parent information service, newsletters, and other publications. It also has local chapters in many towns and cities around the United States, which can be important sources of practical information and support for families.

Address:	The Candlelighters Childhood Cancer Foundation National Office Post Office Box 498 Kensington, MD 20895-0498
Telephone:	301-962-3520 or 1-800-366-CCCF (1-800-366-2223)
Fax:	301-962-3521
E-mail:	staff@candlelighters.org
Internet Web site:	http://www.candlelighters.org

The Leukemia and Lymphoma Society. Financial assistance and consultation services for referrals to other means of local support are offered by chapters of the Leukemia and Lymphoma Society to patients with leukemia, lymphoma, and myeloma. Educational materials for patients and family members are provided through local chapters and the Home Office.

Address: The Leukemia and Lymphoma Society
1311 Mamaroneck Avenue
White Plains, NY 10605-5221
Telephone: 914-949-5213 or 1-800-955-4LSA (1-800-955-4572)
Fax: 914-949-6691
Internet Web site: <http://www.leukemia-lymphoma.org>

Ronald McDonald House Charities. Many major cities have Ronald McDonald Houses where out-of-town families can stay while their children are being treated for a serious illness. The room rates are economical. A social worker may be able to help locate one, or contact the Ronald McDonald House Coordinator at the address below.

Address: Ronald McDonald House Charities
One Kroc Drive
Oak Brook, IL 60523
Telephone: 630-623-7048
Fax: 630-623-7488
Internet Web site: <http://www.rmhc.com>

The National Children's Cancer Society. This independent, national organization provides a broad range of services, including financial and in-kind assistance, advocacy, support services, and education and prevention programs.

Address: National Children's Cancer Society
Suite 600
1015 Locust Street
St. Louis, MO 63101
Telephone: 1-800-5-FAMILY (1-800-532-6459)
314-241-1600 (Program Services)
Fax: 314-241-1996
Internet Web site: <http://www.children-cancer.com>

Selected Reference

1. Ries LAG, Eisner MP, and Kosary CL et al. (eds). *SEER Cancer Statistics Review, 1975-2002*, National Cancer Institute. Bethesda, MD, 2005 (http://seer.cancer.gov/csr/1975_2002).

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Related Resources

Publications (available at <http://www.cancer.gov/publications>)

- National Cancer Institute Fact Sheet 1.4, *NCI's Clinical Trials Cooperative Group Program*
- National Cancer Institute Fact Sheet 1.22, *Cancer Clinical Trials at the National Institutes of Health Clinical Center: Questions and Answers*
- National Cancer Institute Fact Sheet 2.11, *Clinical Trials: Questions and Answers*
- National Cancer Institute Fact Sheet 7.47, *How To Find a Doctor or Treatment Facility If You Have Cancer*
- *When Someone in Your Family Has Cancer*
- *Young People With Cancer: A Handbook for Parents*

National Cancer Institute (NCI) Resources

Cancer Information Service (toll-free)

Telephone: 1-800-4-CANCER (1-800-422-6237)

TTY: 1-800-332-8615

Online

NCI's Web site: <http://www.cancer.gov>

LiveHelp, NCI's live online assistance:

<https://cissecure.nci.nih.gov/livehelp/welcome.asp>

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